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Direct-to-consumer sales of genetic services on the Internet

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Abstract

Purpose—The increasing use of the Internet to obtain genetics information and to order medical services without a prescription, combined with a rise in direct-to-consumer marketing for genetic testing, suggests the potential for the Internet to be used to sell genetic services.

Methods—A systematic World Wide Web search was conducted in May 2002 to assess the availability of genetic services sold directly to consumers on the Internet.

Results—Out of 105 sites that offered genetic services directly, most offered non–health-related services, including parentage confirmation testing (83%), identity testing (56%), and DNA banking (24%); however, health-related genetic tests were offered through 14 sites (13%). The health-related genetic tests available ranged from standard tests, such as hemochromatosis and cystic fibrosis, to more unconventional tests related to nutrition, behavior, and aging. Of these 14 sites, 5 described risks associated with the genetic services and 6 described the availability of counseling.

Conclusions—The availability of direct sales of health-related genetic tests creates the potential for inadequate pretest decision making, misunderstanding test results, and access to tests of questionable clinical value.

Keywords

genetic testing; Internet; direct-to-consumer services; education

Scientists and health care practitioners forecast an era of personalized genetic medicine, when genetic testing will become a standard component of clinical care.^{1,2} However, the risk of misuse of genetic information,³ complexity of result interpretation,⁴ need for counseling services,⁵ lack of adequate physician education in genetics,^{6,7} and questions about test oversight mechanisms⁸ complicate efforts to incorporate genetic testing into primary care. The recent appearance of direct-to-consumer marketing of genetic tests further complicates

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the challenge to use genetic testing in clinical medicine appropriately,⁹ as an increase in consumer interest in genetic testing might place additional stress on the primary care system.

Access to information about genetics is necessary to prepare consumers for genetic testing in clinical medicine. The Internet can be an important source of this information,^{10–15} although there are concerns about both unscrupulous behavior on the Internet as well as the variable quality of health information on some web sites.^{16,17} Additionally, the Internet can be used by consumers to purchase medical products directly, including pharmaceuticals,¹⁸ dietary supplements,¹⁹ and diagnostic tests,²⁰ without the supervision of their physicians. Consumer use of the Internet for direct ordering, as well as for information, coupled with the trend of direct-to-consumer marketing for genetic tests, suggests the potential of the Internet to be used to sell genetic services. The availability of direct genetic testing raises social, ethical, and policy issues.²¹ This study systematically assesses the availability of genetic services offered directly to consumers on the Internet.

MATERIALS AND METHODS

Search strategy

A search of the Internet using Yahoo, Google, and AltaVista search engines was conducted to identify web sites that offer genetic services that consumers can purchase directly without involving their physician. These search engines were chosen because they are the engines that an average consumer might use commonly to seek information.²² The following keywords were used: “genetics” or “DNA” and “test” or “testing,” combined with “home,” “kit,” “disease,” “service,” or “nutrition.” In addition, the Yahoo directory was searched by following the categories of “Business and Economy>Business to Business>Scientific>Biology>Biotechnology>Genetics>Genetic Testing Services,” as was the Google directory, following categories of “Science>Biology>Genetics>Testing and Counseling>DNA Testing Services.” Press releases and news articles found through the above approaches were also investigated to identify sites offering genetic services. All sites that described genetic services that consumers could order through an online form, or via fax, telephone, or e-mail request were included. Sites were excluded if (1) they offered educational information only, without providing a service that consumers were able to purchase, (2) they offered a service that was available only for physician or clinical laboratory use, (3) they offered genetic analysis for plants, livestock, or household pets exclusively, or (4) site content appeared only in a language other than English. When identical sites were found, differing only by website address, a single address for each company was retained for analysis. Twelve searches were conducted between April 23 and May 3, 2002. Searches were stopped when no new sites were identified, and 153 sites were retained for analysis.

Content analysis

Every link on each of the 153 sites was followed and analyzed for content (by SEG) between May 3 and June 3, 2002. A total of 105 sites were unique sites that offered a genetic service directly to consumers. A data collection form was developed by all coauthors together after analyzing a representative sample of 30 sites. The final form collected information about

categories of services, sample collection method, location of sample collection, costs, uses of genetic information, result reporting, disclosure of risks, accreditation, and availability of counseling. Services were categorized as non–health-related when they offered parentage confirmation, identity testing, and DNA banking, and as health-related when they offered genetic information related to a consumer’s current or future health status. All 105 sites were analyzed by SEG and fifty of these sites were also coded by either BSW or SCH. Those few differences in coding that were identified were discussed until agreement was reached. Data were entered into a Statistical Package for the Social Sciences 10.0 database, and descriptive statistical analysis was performed.

RESULTS

General characterization of services

A total of 105 Internet sites offered a genetic service to consumers; 81 listed addresses in the United States, 17 listed international addresses, and 7 listed both domestic and international addresses. Sites with international affiliations were from Canada (13), the UK (4), Australia (2), Hong Kong (2), Germany (1), South Africa (1), and Malta (1). Ninety-six sites offered non–health-related genetic services, such as parentage testing, identity testing and DNA banking; 14 sites offered health-related genetic testing (Table 1).

Costs for genetic services ranged from \$14.95 for an at-home DNA banking kit to \$3,200 for mitochondrial DNA maternity testing. The cost for the most commonly offered test, listed on 67 sites, a test for parentage confirmation using samples from the mother, putative father, and child, ranged from \$150 to \$610, with a mean cost of \$349.

The methods by which consumers would receive their test results, which were specified on 60 sites (57%), included: mail (47), e-mail (13), online (11), and telephone (6).

Some sites offered consumers claims that their service was approved by some accrediting organization or professional society, including the American Association of Blood Banks (45), the Center for Medicare and Medicaid Services (CMS) through the Clinical Laboratory Improvement Amendments (CLIA) (26), the American Society for Histocompatibility and Immunogenetics (ASHI) (8), the New York State Department of Health (6), and the National Forensic Science and Technology Center (5). Single sites featured claims of approvals by the College of American Pathologists, the Immigration and Naturalization Service, the National Institute of Standards and Technology, and the International Society of Forensic Genetics.

Specific risks relating to testing that were mentioned on sites included: potential for emotional reactions (8), impact on the family (5), genetic discrimination (4), inconclusive results (3), using samples for some other purpose without the consumer’s consent (2), and risks to consumers’ health if they change their behavior as a result of new genetic information (1). Although the risk of a breach of confidentiality was described on 4 sites, 73 sites assured the consumer that the service is “confidential.”

Four sites described physician consultations available with the service; 7 sites described genetic counseling services available for consumers.

Non–health-related genetic tests

Sites that sold parentage and identity confirmation genetic testing (94) described a variety of consumer uses of the information (Table 2). Many sites (68) described legal uses of their service, including identity confirmation for immigration, inheritance, custody determination, and child support. Genealogical uses (15) involved determining the degree of relatedness between samples or tracing samples to ancient origins, including the Vikings, Native Americans, and the Cohanim (a genetically distinct lineage of Jews). Other more idiosyncratic uses included infidelity testing, copyrighting DNA, and creation of personal identity cards. Sites marketing DNA banking described future health-related uses of this service, often for testing not yet available or technically feasible. Sites described the possible health-related uses of DNA banking: “[...] routinely check as genetic tests are developed for conditions such as breast cancer, Alzheimer’s, and Parkinson’s disease,” and “with your DNA sample on file, a member of your family could benefit with early diagnosis or disease prevention.”

Health-related genetic tests

Table 3 lists the 14 sites that directly marketed health-related genetic tests to consumers and the tests offered. Of these, 7 sites (sites 1 to 7) allowed consumers both to order the service directly and receive their results without involving the consumer’s physician. The company that offered tests for DNA damage levels also marketed a “nutraceutical” remedy that would “increase DNA repair, decrease DNA damage, and improve immune function...which allows our genetic blueprint to function more effectively.” The site that offered genetic testing for addictive behavior also offered “nutraceutical” therapies. The site described one purpose of their service: “Are you concerned about your children’s future? Does your child have the genetic trait that leads to disruptive and addictive personalities? DNA testing can help you to understand and manage a child’s behavior before it gets out of control.” The site that offered personalized behavior and nutrition advice disclosed that their genetic profile would be useful for those who “need extra motivation,” but would have “little value” for people already conscientious about their health and diet. The site offering pharmacogenetic testing described the test’s use for determining consumers’ efficiency at metabolizing common drugs, including Loratadine (Claritin), Fluoxetine (Prozac), and Sildenafil (Viagra). One site offered at-home test results for α -1-antitrypsin deficiency as part of a university research study assessing patient perceptions of learning genetic information.

Four sites provided instructions for consumers to order genetic tests, but required that the results be received by a physician (sites 8 to 11 on Table 3). Three other sites (sites 12 to 14 on Table 3) required consumers to inquire for information about ordering tests. One of these sites marketed genetic profiles to assess “oxidative stress levels” that might allow consumers to tailor vitamin supplements, nutrient intake, and skin care products.

Availability of multiple services

Sixty-two sites (59%) offered more than one category of genetic service. Of the 14 sites offering health-related testing, five also offered some combination of non–health-related services (Table 3). In addition, of the 91 sites directly offering only non–health-related services, five sites advertised health-related genetic services available to consumers through

their physicians, and six sites had content that projected adding health-related testing options in the future. According to one such site: “as the connection between genes, ancestry and health become better understood and new technologies are developed, additional information about gene testing will be available [on this site]. We are committed to bridge a transition from the scientific research lab bench to a reliable and high-quality service for the consumer.”

DISCUSSION

Our findings demonstrate that although Internet sites primarily offered non–health-related genetics services to consumers, a small number of Internet sites directly offered health-related genetic tests. The availability of health-related genetic tests through the Internet raises three concerns: insufficient information for pretest decision making, the potential for misunderstanding results, and the availability of genetic tests without clinical value.

The process of ordering health-related genetic tests on the Internet may be problematic. Sites infrequently described the risks commonly associated with genetic testing, such as concerns about privacy and familial implications. Furthermore, few sites described whether or not there were protections related to sample storage, withdrawal, and future use. With only limited risk disclosure as well as exaggerated benefits described on some sites, consumers may not have the relevant information they need to make their decision to pursue testing. Because interest in testing for standard clinical genetic tests has been shown to decrease after educational interventions,^{23,24} consumers’ initial interest in ordering a genetic test on the Internet similarly might be lessened after more thorough pre-test information.

The process of receiving results through these Internet services also raises concerns. Genetic test results can be difficult to interpret.^{4,25–27} When results are provided directly to consumers without adequate interpretation, consumers may be at an increased risk for misunderstanding the meaning or implications of their test results. Although genetic counseling or physician consultation might help consumers better appreciate the meaning of their test results, these options were only available on six of the 14 sites offering health-related genetic testing. One site went so far as to include in a disclaimer: “[we] will not be responsible in any manner for providing any advice or analysis regarding the Test Results,” encouraging consumers to contact a health care practitioner for result interpretation.

Although four sites required the results to be sent to consumers’ health care practitioners, thus involving them in discussion, this approach may be insufficient. Clinicians have varying degrees of knowledge about genetics and varying abilities communicating genetic information.^{7,28,29} For consumers to have the greatest likelihood of understanding the implications of a health-related genetic test, clinicians with appropriate genetics knowledge and experience should be involved in this process.

The Internet provides a context through which unconventional applications of genetic testing can become commercially available. Although some sites offered health-related genetic tests that are associated with routine clinical practice, including tests for hemochromatosis, cystic fibrosis, and alpha-1-antitrypsin deficiency, others offered more novel uses of genetic tests,

including tests related to nutrition, skin care, addictive behavior, and aging. For these novel tests in particular, neither the likelihood with which a test predicts a condition (“clinical validity”), nor the likelihood that the test will lead to an improved health outcome (“clinical utility”), are established.³⁰ Premarket test regulation could prevent tests from becoming commercially available before there is sufficient evidence of their clinical value; however, such regulation is currently lacking.³¹ Even without such oversight, few health care practitioners are likely to offer tests with unconfirmed clinical validity or utility; however, such tests can be made readily available on the Internet.

When consumers independently purchase tests with unconfirmed clinical validity or utility, they will spend money on tests with limited value and put themselves at risk for harm. Test results might influence consumers to alter their behavior adversely, such as inappropriately changing their diet or medications. Consumers might pursue genetic testing in lieu of other appropriate treatment, such as psychological counseling and pharmacologic interventions for addictive behavior. In addition, statements describing the benefits of testing, such as “DNA testing can help you to understand and manage a child’s behavior,” may inflate consumer expectations about the health outcomes they can anticipate from testing.³² Consumers’ exaggerated evaluation of tests’ clinical utility is especially concerning when considering those services that sell consumers unconventional “remedies” associated with their test results. Finally, test results could cause consumer anxiety and confusion,²⁷ especially if health care practitioners are unable to interpret the results of unconventional tests without established clinical value.

It is likely that more Internet sites will offer direct sales of health-related genetic services in the future, given that 59% of sites already offered more than one category of genetic service. More specifically, 10 sites offered both non–health-related genetic services and health-related genetic services, and six of the sites offering DNA analysis for non–health-related applications described plans to offer health-related services in the future. The persistence of these services will depend largely on their uptake by consumers. Indeed, consumers might perceive the private at-home context to be appealing, particularly those who worry about genetic discrimination in the clinical setting.³³ If there is consumer demand for these services, the availability of health–related genetic testing on the Internet will expand.

The potential for consumers to face risks from direct access to health-related genetic tests suggests the importance of oversight. Regulatory attention becomes increasingly important given the potential for direct sales of genetic testing on the Internet to expand. In their efforts to protect consumers from claims made in marketing for health products in the United States, the Food and Drug Administration or the Federal Trade Commission might appropriately apply their regulations to Internet services’ claims about the utility of genetic tests.^{34–36} Sites offered claims of CLIA certification or of accreditation by other agencies, lending the appearance of credibility to their services. However, whereas CLIA certification might suggest that a test result has analytic validity, such accreditation does not guarantee that the test is clinically meaningful. Furthermore, CLIA regulations offer only limited guidance about which individuals are authorized to order tests.³⁷ Although some states have developed laws that restrict the ordering of laboratory tests to health care providers as opposed to patients (New York, for example, restricts medical test ordering to “qualified

practitioners” only),³⁸ other states do not address this issue. Steps toward regulation and control of the direct provision of genetic tests have been taken recently in the United Kingdom.³⁹ However, because Internet services create an international market, blurring state and national boundaries, it may not be easy to apply regulatory restrictions to Internet marketing.²¹

There are three limitations of this study. First, the study does not measure consumer behavior, so actual use of these sites or their impact on consumers is unknown. In addition, the study does not assess company behavior, only site content, so the nature of any communication between company representatives and consumers is not clear from our study. Third, this study examines Internet practices at a particular point in time through a limited series of searches. Internet content is frequently revised, and entire sites are readily created or removed from the Internet, so there will be changes and additional sites that are not reflected in this data.

The direct provision of genetic tests to consumers through the Internet, as well as broader concerns about direct-to-consumer advertising for genetic tests,⁹ will become increasingly important issues as consumers become more interested in pursuing genetic tests in their health care. Although only 14 sites identified in this study offered health-related genetic tests, these sites are accessible to the Internet-savvy consumer who is interested in genetic testing. Thus far, there have been only positive anecdotal accounts of individual patient use of these services,^{40,41} as well as testimonials on the sites. Future research on consumer use and the impact of these services on consumers will be necessary to conduct a more complete analysis of the implications of this practice. Postmarket, as well as premarket regulatory attention to clinical genetic tests, including an assessment of Internet sites, is needed to protect consumers from exaggerated claims and from tests with little clinical value. Furthermore, the Internet might play an important role in providing consumers and physicians access to information about the clinical value of genetic tests, but only when educational information is accurate and current.¹⁵ Until there are data to support that the direct sale of genetic services does not put consumers at risk, health-related genetic testing should not be routinely available on the Internet for consumers to order or receive results without the involvement of an appropriate health care practitioner.

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Table 1Characteristics of Internet sites offering direct-to-consumer genetic services ($n = 105$)

Characteristic	No. of sites ^a
Type of genetic service	
Parentage testing	87
Identity testing	59
DNA banking	25
Health-related genetic testing ^b	14
DNA collection method	
Buccal swab	96
Passive collection ^c	32
Venipuncture	29
Hair extraction	10
Finger/heel pricks	9
Location of sample collection	
Home	77
Other site (clinical laboratory)	65
Patient's primary care clinic	10
Traveling (mobile) facility	8

^aCharacteristics were not mutually exclusive.^bHealth-related genetic testing excludes DNA tests for somatic mutations in tumors or DNA testing for presence of pathogens.^cPassive collection is defined as DNA samples taken without deliberate assent from the individual through varied sources including blood spots, cigarettes, chewing gum, hair, soda cans, envelopes, undergarments, towels, or bedding.

Table 2Uses described on sites for parentage and/or identity confirmation ($n = 94$)

Uses	No. of sites ^a
Immigration	44
Twin zygosity	43
Inheritance or estate disputes	36
Adoptive relationship	27
Forensics (criminal investigations)	26
Missing person cases or kidnapping	22
Custody determination	15
Genealogy	15
Proof of infidelity	14
Child support	12
Native American tribal rights	5
Parentage for <i>in vitro</i> fertilization cases	4
Social security benefits	4
Newborn identity	3
Parentage for medical history determination	3
Verification of identity for drug testing	2
DNA copyright	1
“Gift for person who has everything”	1

^aUses were not mutually exclusive.

Table 3

Sites that Offered Health-related Genetic Services Directly to Consumers^a

Company (Location) and Web address	Purpose of health-related test (particular genes or approach, if specified)	Cost(s)	Risks described	Consultation services available	Nonhealth + related services offered
1. Alpha One (U.S.) http://www.alphaone.org/news/initiatives/alpha1_coded_testing_trial.html	α -1-antitrypsin deficiency (research trial of risks and benefits of learning genetic information)	Free	Genetic discrimination, breach of confidentiality	Physician	None
2. Doc Blum (U.S.) http://www.docbluminc.com/	Susceptibility to addiction (dopaminergic genes)	\$275	None	None	None
3. Genelex (U.S.) http://www.genelex.com	Drug metabolism (cytochrome p450)	\$250	Risk of behavior changes based on test results	None	Paternity, Identity
4. Healthcheck U.S.A. (U.S.) http://www.healthcheckusa.com	Hemochromatosis	\$165	None	None	None
5. Optigene-X (U.S.) http://www.optigene-x.com	Aging (DNA damage)	\$140	None	Physician	None
6. Sciona (U.K.) http://www.sciona.com	Nutrition and lifestyle advice (9 genes that influence detoxification, free radical removal, vitamin B6, B12, and folate metabolism, and alcohol metabolism)	\$175	Emotional consequences, genetic discrimination, breach of confidentiality	None	None
7. Health Screen America (U.S.) http://www.healthscreenamerica.com	Hemochromatosis	\$169	None	Physician	Banking
8. Kimball Genetics (U.S.) http://www.kimballgenetics.com	Hemochromatosis; susceptibility to thrombosis (factor V, factor II); susceptibility to cardiovascular disease (Apo E); fragile X; susceptibility to periodontal disease (interleukin-1)	N.A. ^b	None	Genetic counseling	None
9. Baylor Health Care System (U.S.) http://www.baylorhealth.com/newbornscreening/	Supplementary newborn screening	\$25	Inconclusive results	Genetic counseling	None
10. Neo Gen (U.S.) http://www.neogenscreening.com	Supplementary newborn screening	\$25–\$60	Inconclusive results	None	None
11. New Screen (U.S.) http://www.newscreenest.com	Supplementary newborn screening	N.A. ^b	None	None	None
12. Badger-Hawkeye Red Cross (U.S.) http://www.a2zdna.com	Susceptibility for ankylosing spondylitis; hemochromatosis; narcolepsy; type 1 diabetes (HLA typing)	N.A. ^b	None	None	Paternity
13. Gene Link (U.S.) http://www.bankdna.com	Oxidative stress profile; susceptibility to obesity; susceptibility to osteopenia	N.A. ^b	None	None	Banking
14. Datagene (U.S.) http://www.datagene.com	Carrier screening for cystic fibrosis, sickle cell anemia, Tay-Sachs; fragile X	N.A. ^b	None	Genetic counseling	Paternity, Identity Banking

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Sites 1–7 allowed consumers to order the service directly and receive the results without involving the consumer’s physician. Sites 8–11 allowed consumers to order tests but required results to be received by a physician, and sites 12–14 required consumers to inquire for ordering information.

Not Available. These sites required consumers to call for prices.